

# PARTNERS IN THE JOURNEY

## 2022 OUTLOOK



Children's Cancer  
**PARTNERS**™ OF THE  
CAROLINAS

Supporting Families Through the Journey

## SOME THINK ASKING FOR HELP IS HARD.

We do it all the time...we never stop. We ask every healthcare professional who detects cancer in a child to make sure that a child's family is connected with Children's Cancer Partners of the Carolinas to ensure they have all the help they need to complete their difficult cancer journey. Sometimes those professionals get too busy, especially in this pandemic, and so we ask others to help us identify children and families in need – school officials, family and friends, anyone really. You might be the one to make that connection.

We ask caring people to help us gather all the resources of "time, talent and treasure" needed so Children's Cancer Partners can always respond to the needs of the children and their families. Every dollar in our budget used to belong to a caring person or organization that decided to make a difference in the life of a child.

Surprisingly, we spend a lot of time persuading parents, perhaps too proud or private, that it is their right, and indeed their duty, to ask for help – and accept it.

### Here is what we tell them:

- You will have more time and energy to care for your sick child, and for other family members if you allow us, and others in your community, to help.
- No one budgets for cancer – don't be embarrassed that you didn't either.
- There are things like grocery shopping, cleaning, driving, cooking – that others can do, but so many things that only a parent can do for their

sick child, or for their other healthy children at this time. Do what is important – let others pitch in on the rest.

- You are in the midst of a family crisis, for sure, but it will not last forever. There is a "new normal" to which you must adjust, until your child's journey is completed. But right now, there are things Children's Cancer Partners and others can do to help you and your family.
- It is upsetting for everyone around you when your child is battling cancer. Helping is our mission, but all the caring people around you will feel better when they can do something useful, too. Please let them. Let your child see the power of caring. It helps them and you, and it helps those who are eager to share their care.

Asking for help can seem hard to some; giving and getting it, too. That is not the way for Children's Cancer Partners of the Carolinas. You would not be reading this if you did not believe in the partnership between caring people, and those battling childhood cancer.

We are proud to share with you our OUTLOOK for 2022. We hope you will partner with us.



*Ki Young Chung*

Ki Young Chung, MD  
Board Chair



*Laura*

Laura Allen  
Executive Director

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FOR MORE INFORMATION, PLEASE VISIT [WWW.CHILDRENSCANCERPARTNERS.ORG](http://WWW.CHILDRENSCANCERPARTNERS.ORG)

## FAMILY FEATURE

In February 2021, Burkley was diagnosed with Stage IV Neuroblastoma, cancer that forms in certain types of nerve tissue, at the tender age of three. She had a large tumor in her abdomen with metastasis to her lymph nodes as well as her bone marrow. Genetic testing found the tumor to be the more aggressive form of Neuroblastoma, giving Burkley a 50% chance of survival. In February, she had a very successful surgery which removed the tumor and bulk of the malignant abdominal lymph nodes. She then underwent 6 rounds of inpatient chemotherapy, a bone marrow transplant (which was 7 weeks of inpatient at the Medical University of South Carolina), and radiation. She is now undergoing monthly inpatient immunotherapy. In June 2021, her testing showed no evidence of disease and thankfully has had no evidence of disease since.

Children's Cancer Partners has supported Burkley and her family during her entire journey. CCP aided her family with the cost of gas, parking, and meals – three expenses that add up quickly. This financial burden would have posed difficulties for the family if CCP was not there to support them. Additionally, monthly check-ins on Burkley means so much to the family. "CCP means that we have a little less worry in our otherwise very stressful life," states Burkley's mom. "When your child is diagnosed with cancer, you drop everything to be with your child. This means we missed countless days of work and yet required more money to pay for travel and food. CCP has been an incredible charity to aid us with these costs and help relieve that burden."



## PARTNER FEATURE

Children's Cancer Partners of the Carolinas and White Oak Management, a provider of assisted living, short term rehabilitation, nursing homes, independent living, and memory care throughout the Carolinas, have a long history of partnership. White Oak Management has sponsored events such as Cribb's Kitchen Annual Burger Cook-Off and Docs Who Rock. Most recently, White Oak Management has partnered with CCP by giving funds to the COVID-19 Emergency Fund to continue to support Carolina children battling cancer. This partnership has continued to grow through the alignment of each organizations' missions.

"We believe in Children's Cancer Partners and its mission to help children and their families battling cancer," states Doug Cecil, President of White Oak Management. "CCP's level of support and responsiveness to families is amazing. We are proud to partner with CCP. They make it possible for families to deal with such a terrifying diagnosis that comes with great medical costs, not to mention the costs associated with travel for treatment. We, at White Oak, hope our contribution allows them to receive the care they need with as little stress as possible on both the child and their family," states Cecil.



White Oak Manor



Childhood cancer is everywhere. Every one of these 1,639 dots (as of January 1, 2022) is a brave child fighting for their life. Every day, another 2-3 more children are diagnosed in the Carolinas.



## LEGEND



**Pediatric Treatment Center**



**CCP Children**



**Children's Cancer  
PARTNERS™ OF THE  
CAROLINAS**

Supporting Families Through the Journey

# INTERESTING NUMBERS

## LAST YEAR...

**893 hotel stays** for treatment

**1,720,165 treatment travel auto miles** reimbursed

**11 states** outside of the Carolinas, where children went for specialized treatment at 24 different research centers

**2,378 knitted blankets, hats, scarves** donated from 21 states and 4 countries

**\$101,720 in volunteer service** donated, based on I.R.S. valuation of \$25.43 per hour and estimated 4,000 hours from CCP volunteers

**DID YOU KNOW?** We began in 2001 as the Children's Security Blanket, and it has been our custom ever since to present each new child with a blanket when they enroll, signifying us "wrapping them in hope and love." We ran short of blankets in 2019 and a social media appeal went viral, reaching over 1,000,000 people on 4 continents. Blankets began arriving by the hundreds, many with heartwarming messages of family joy, grief and hope!

## EVERY YEAR...

**75% of childhood cancer families** suffer the loss of half or more household income during their treatment journey

**\$40,000+** is the average cost of a single hospitalization for childhood cancer

**99% of childhood cancer survivors** experience some type of chronic lifelong health complication

**8,000 or more child-patients, caregivers and siblings** will benefit from CCP assistance this year, based on projected 2,000 children enrolled and our support of the entire family (average 4.2 per household)

**0 (ZERO) – the number of childhood cancer patients turned away, or family requests declined**



# OUR "BIG 5" FACTS

1

**Cancer** remains the #1 disease killer of children.

- 17,000 new cases in America every year and 700+ in the Carolinas
- Diagnoses have risen steadily for the past 40 years
- Pollution and carcinogens are the bad news, but more awareness and earlier detection is the good news

2

**There are too few pediatric locations.**

- 3 in South Carolina
- 6 in North Carolina
- Just over 200 nationwide

3

Children of rural and poor families face **3x greater risk** for missed or late diagnosis, incomplete treatment, and relapse.

#### WHY?

Southeast states are in the bottom 1/3 nationwide for:

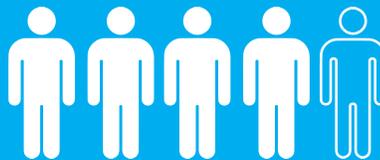
- a) public health care
- b) higher cancer incidence
- c) rural poverty

\$\$

4

**Barely 4% of all cancer research dollars are for pediatrics.**

Most current treatments were approved before 1990, half before 1980! Clinical trials of new treatments begin 6.5 years after adult trials.



**1 in 5 children** will not survive 5 years after diagnosis

5

- The average child cancer victim loses 71 years of life expectancy compared to the 15 years for average adult victims
- Nearly 60% of childhood cancer survivors experience severe or life-threatening complications in adulthood

**24 hrs** | CCP responds to new referrals within 24 hours

Data sources include Children's Oncology Group, National Cancer Institute, and the American Childhood Cancer Organization

IMPACT IS ...

## YOU & YOUR GIFTS, MAKING A DIFFERENCE!

- Helping 1,639 brave children last year – 2,000 or more this year
- Supporting our children by giving over \$2,367,000 last year
- Putting your good name alongside ours as an inspiration for others
- Taking the time to understand the unique challenges of childhood cancer
- Sharing with others what you learn about the #1 disease killer of our Carolina children
- Responding so heartily to our invitations to do even more
- Building our COVID-19 Relief Fund so our family support was never interrupted
- Making this OUTLOOK report possible by lifting us into our THIRD DECADE
- Giving us the courage to promise even more in 2022

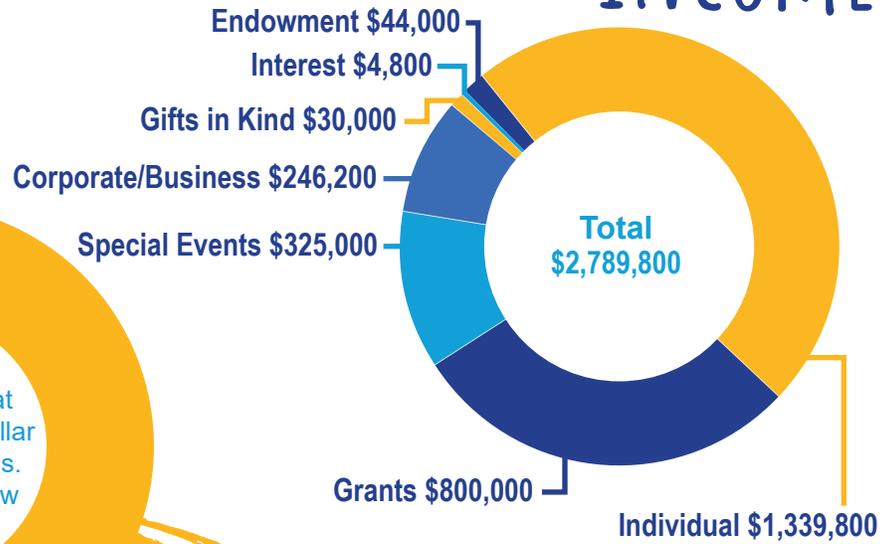
We thank you for your gifts and grants, and hope you know the difference you make. This 2022 OUTLOOK report seemed the perfect way to THANK YOU AGAIN by showing you what we are prepared to do for the children in our program, and the hundreds more who will join them this year.

Every dollar we transform into our unique Carolina Childhood Cancer Safety Net used to belong to a caring person or organization who chose to share their good fortune with a frightened child. That is how we will keep all of the promises you see here – with your caring and generosity.

# THANK YOU!

# OUR OUTLOOK 2022

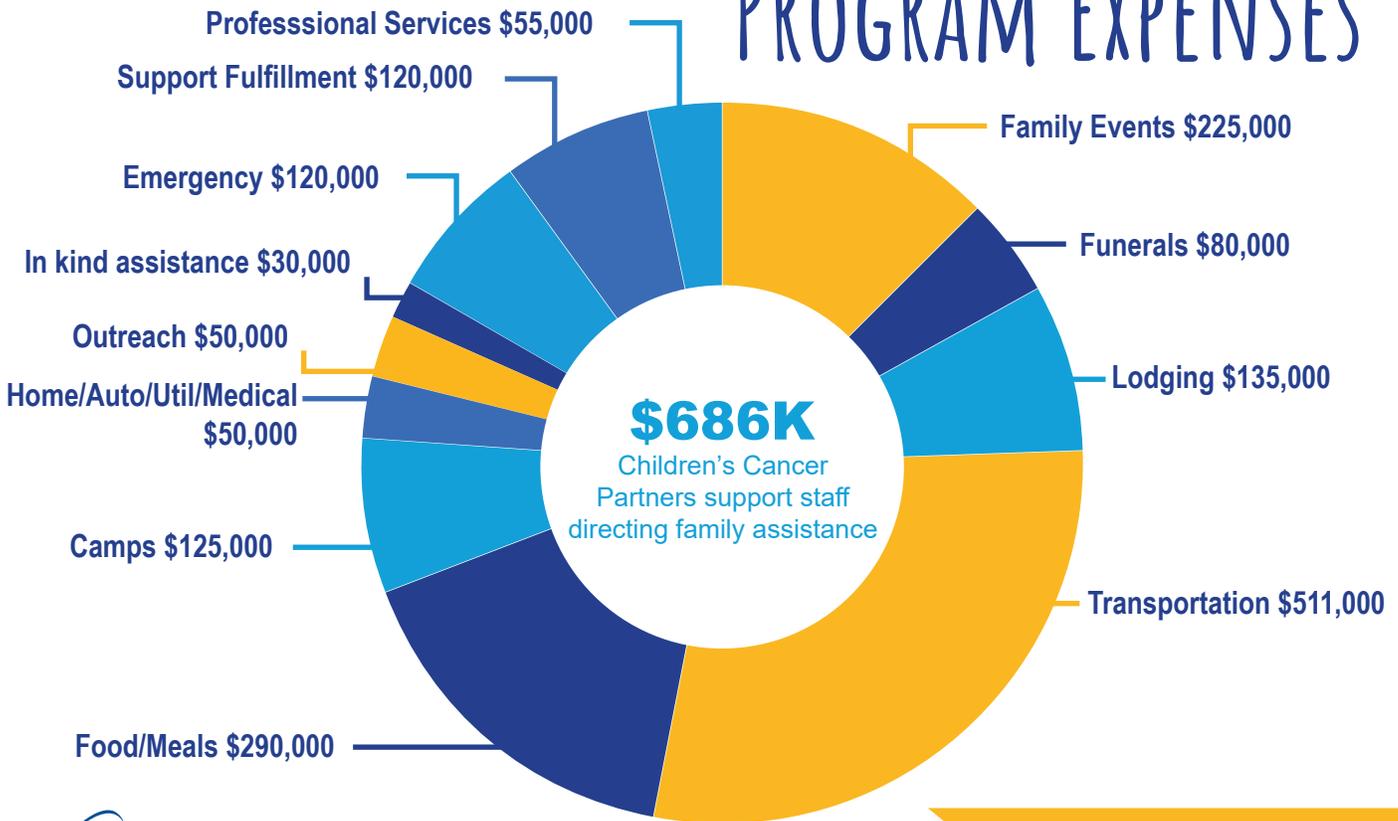
## INCOME



## EXPENSES



## PROGRAM EXPENSES



CCP prides itself on financial transparency.

Our latest audit and 990 is available on our website.

## FAMILY FEATURE

Then six-year-old Joseph was diagnosed with Medulloblastoma, a type of brain tumor that starts in the lower, back part of the brain, on September 12, 2020. Joseph began a clinical trial, Head Start 4 Protocol, at Medical University of South Carolina (MUSC) in Charleston. A stent was placed initially to alleviate pressure, and then brain surgery was done to remove the mass. From there, Joseph began 3 very intensive rounds of chemotherapy followed by a stem cell transplant and a final round of chemotherapy. Joseph also received proton radiation at the University of Florida Proton Institute in Jacksonville, Florida. He spent 6 weeks in Jacksonville, almost 4 hours away from home. Joseph's entire treatment took over a year with follow up MRIs every 3 months since completion.

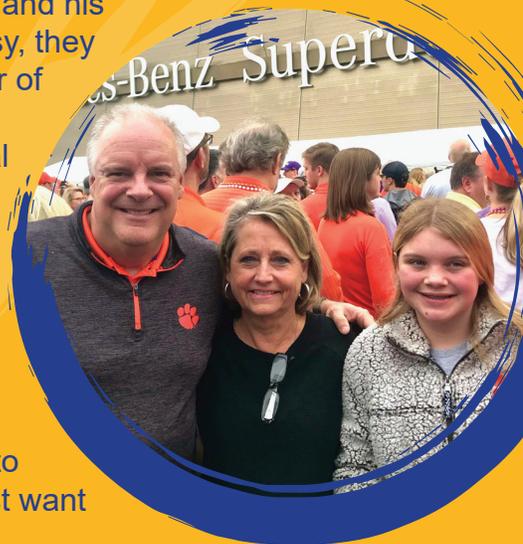
During his course of treatment, Children's Cancer Partners helped with parking passes for the hospital and reimbursement for food and travel. The family received regular check-ins from their family advocate to see how Joseph was doing and if there was any way they could help. "CCP was another group of people vested in my child's well-being and helping our family as we encountered the unknown," states Joseph's mom. "They supported our family when we couldn't even articulate the support we needed. CCP is a caring group of individuals who do their best to assist with making a journey no family ever plans for, a little bit easier." Children's Cancer Partners will be alongside Joseph and his family, like the other families, until he turns 21.



## VOLUNTEER FEATURE

Children's Cancer Partners Board Member, Glenn Cash, and his wife, Kelly, have custody of their 14-year-old granddaughter, Lydia. Lydia is an outstanding tennis player and last Fall was one of two freshmen at Riverside High School to make the varsity tennis team. Early in 2020, however, Lydia had a huge setback. It was March of that year when she complained of back pain or what was believed to be sciatica, due to muscle strain related to a recent fall she had while playing tennis. After weeks of physical therapy, the pain did not go away, in fact, it got worse. Finally, after a bout of sleepless nights, Lydia was sent for an MRI. The results shocked Glenn and his wife to their core – a mass was discovered in her lower spine. After a biopsy, they were told it was a malignancy called Myxopapillary Ependymoma, a cancer of the spine. Lydia went through a major back surgery and had to go through multiple radiation sessions. Today, she is healthy. She will endure bi-annual MRIs for an interim period and likely will endure an MRI once per year for the rest of her life.

Glenn reflects on their experience with childhood cancer. "While Kelly and I did not need the assistance of Children's Cancer Partners, I have an understanding of how a child with cancer affects the whole family. It's devastating for the family and I cannot imagine the fear it brings to a child. Children's Cancer Partners provides resources to enable the family to get to the end zone from a treatment aspect. This is critical to save lives and I just want to give back my time for those less fortunate than Kelly, Lydia and I."





# kidz IN LIDS™ INCLUSION PROGRAM

Kidz in Lids mobilizes students to show concern for other local youth who are in a life or death struggle with cancer. **IT'S SIMPLE** – caring kids bring \$1 to school and get to wear their favorite hat throughout the school day. Adults chip in \$5 and get to wear blue jeans in school.

## CIVICS

Kidz in Lids allows healthy schoolchildren to understand the fight that children with cancer face every day, while also learning leadership skills and taking pride in their school.

## EMPATHY

Kidz in Lids is a true lesson of empathy. It teaches children that supporting their peers with cancer is not only the best thing to do, but the right thing to do.

## COMMUNITY

Kidz in Lids provides children with cancer a sense of community — the program allows healthy schoolchildren to fight alongside their peers with cancer and support them.



To become a sponsor of or to participate in Kidz in Lids, please reach out to:

## KATE MORROW

[Kate@ChildrensCancerPartners.org](mailto:Kate@ChildrensCancerPartners.org)

Cell: 803-608-2505

Office: 864-582-0673

# COMING UP IN 2022

## IN-PERSON EVENTS

You'll be able to attend the Upstate's Juiciest Throwdown Cribb's Kitchen Burger Cook-Off in Downtown Spartanburg on April 30 and rock out at Docs Who Rock on October 22. We are excited to be hosting in-person events once again.

## ENDOWMENT FUNDS

We currently have endowment funds in four foundations across the Carolinas: Central Community Foundation, The Foundation of the Carolinas, Spartanburg County Foundation and Triangle Community County Foundation. The Lucy and Tom Russell Urgent Needs Fund supports children who travel great distances to receive treatment.

## CHRISTMAS SPECTACULAR

We are looking forward, in December, to hosting our first in-person Christmas Spectacular in both Spartanburg and Raleigh again this year. Out of precautions due to COVID-19, we were not able to gather together with our families in 2021. We sent families a holiday surprise, which consisted of a gingerbread house kit to create as a family.

## DIY FUNDRAISERS

We rely 100% on the generosity of others. We are so grateful for the numerous Do-It-Yourself (DIY) Fundraisers hosted in 2021, from yoga and fitness events to in-kind donation drives. Have an idea of a DIY fundraiser? We would love to be the recipient! We are very excited about an upcoming golf tournament in Durham, NC in April, a dive shop event in Spartanburg, SC, and much more!



## CAMP RACHEL

We'll host our second annual bereavement camp, Camp Rachel, in September. Named in honor of one of our fallen superheroes, Camp Rachel brings together families from North and South Carolina who have lost children to cancer.

## CAMP VICTORY

Camp Victory, in its 15th year, will be held at Camp Cole, located just outside of Columbia, SC, which is a great location for our families. We are able to continue Camp Victory traditions and will host another great Camp Victory in early June.

## FAMILY EVENTS

Since 2020, we have been hosting virtual monthly family game nights with help from Optimist International. While we will still be hosting virtual events, we look forward to hosting in-person events this year. Our first of the year will be Operation Fighting Spirit hosted by the Celebrate Freedom Foundation in Columbia, SC. This will be followed by the favorite Fishing Rodeo and a day at Hope Remains Ranch, an equine therapy ranch, in the summer.

## CHILDREN'S CANCER PARTNERS STAFF

Laura Allen, Executive Director  
Tom Russell, Founder  
Dania Beck, Director of Philanthropy  
Shannon Brown, LISW-CP, LSW, Director of Family Programs  
Kim Melick, Director of Operations  
Kate Morrow, Director of Development  
Debi Abbott, Donor Relations Manager  
Carla Fowler, MS, Family Advocate Manager  
Blake Stafford-Gomez, Family Programs Manager  
Erica Buff, MS, Communications Coordinator  
Laura Dellicker, MSW, LCSW, Family Advocate  
Becca Waldorf, AmeriCorp VISTA

You can reach our staff at  
[Info@ChildrensCancerPartners.org](mailto:Info@ChildrensCancerPartners.org)

**Children's Cancer Partners of the Carolinas**

900 S. Pine St. Suite F  
Spartanburg, SC 29302

ENVELOPE SALUTATION  
ADDRESS LINE 1  
ADDRESS LINE 2  
CITY, STATE POSTAL CODE

# OUR MISSION

Children's Cancer Partners provides comprehensive support and loving compassion to families whose children are battling cancer to improve their overall quality of life. We help families in South and North Carolina overcome distance and cost barriers, so their child's care is timely and complete. Our help for children battling cancer is **IMMEDIATE, COMPREHENSIVE** and **CONTINUOUS** until each child reaches age 21.

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# CONNECT WITH US!

**North Carolina:**

404 Hunt Street, Suite 300 MB #4  
Durham, NC 27701  
919-530-9366

**South Carolina:**

900 South Pine Street, Suite F  
Spartanburg SC 29302  
864-582-0673



**On Social Media**

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SCAN TO LEARN MORE  
Special thanks to Mellco Creative  
with the design of this publication.